

Getting Started



So what's next for you?

You are probably thinking more about what you want to do with your friends this weekend, than about the home work that is due tomorrow. Since you have some special medical needs, those are also on your mind. Sometimes you may feel your parents are still treating you like you were a little kid; and at other times you may feel like all the things you have to do and think about are just too much. It's easy to forget how much you have learned and how much you have changed over the last few years.



The first step in being more in charge of your health, is to take a look at who you are now, and how much you have changed since you were a kid in middle school.



What You Can Do

Now is a good time to learn as much as you can about your health care needs. Here are some things you should be able to do by the time you are ready to start high school.

Tell someone the name of your health condition (your diagnosis).



Make a list of your medications (with their correct name) when you take your meds and why.



Tell someone what you have to do to stay healthy (You probably have heard your doctor tell you these things, but most teens expect their parents to remember all this stuff).

Don't Forget

If you want to be able to do things on your own, like drive a car, go to the mall, or spend the weekend at a friend's house, you need to be more in charge of your health. Also, you need to know what to do in case of an emergency and your family is not around.

is a good time
to talk to your
family about taking
more responsibility for
your own health care.
Remember, parents
are more likely to give
you more privileges
when you show them
that you are more
responsible.

Look at the list below and circle the things you could take more responsibility for.

Taking my medications when I am supposed to.

Order my medications when I need more.

Call to make an appointment with my doctors.

Read books to learn more about my condition.

Look things up on the Internet about my condition.

Help keep a notebook that has information about my health care.

sponsibility for:		 	
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Growing up can be really great: new friends and being old enough to do more things on your own.

And it can be really hard: more responsibilities; finding friends who are really friends; dealing with lots of changes in you and your life. And having a chronic health condition and maybe feeling that you are a little different can make it even harder.

One thing that many teens do to deal with all the changes, and keep in touch with who they are and what they are feeling is to keep a journal. Some write in a spiral notebook and some type into a computer. But they all find that spending the time to put thought and feelings into words and onto paper can really help make sense of what is going on.

Expressing your feelings in writingcan help to keep things that bother you
from going around and around in your
head. You can also write down your goals — for school — or
for taking responsibility of your own health care — Writing down
these goals can help you focus on what is really important to you
and will help you see how much progress you are making.

Try it for yourself! What do you have to lose?









Growing up with special health care needs can present many challenges. However, young people with chronic health conditions and disabilities have been able to meet these challenges and reach their goal of being independent and having a good job. To be successful, they had to:

- TAKE RESPONSIBILITY FOR **THEMSELVES**
- MANAGE THEIR OWN HEALTH CARE
- BE AS PHYSICALLY FIT AND HEALTHY AS POSSIBLE







What other teens Growing up are saying about with a chronic health condition



Prior to age 16 my parents were very involved and my doctors talked to my parents about my surgeries and I kind of went along with that. But at 16 doctors started to talk to me... and by the time I was 18, I was making the decisions.

— Jeff



I like the fact that (my health) is my responsibility. I see that as freedom.

-Amy



My mom taught me how to interact with health professionals and to tell them what I need and what I want, because I know me the best and how my body works...and how they can help me.

— Laura



I think you should be thinking about your future, no matter how old you are, so you can make that transition (to being an adult) more easily. Good health to me means I can live a long and happy life and fulfill all my dreams... and maybe a few more...

— Loretta



A lot of times when you are in the room with your parents and the doctor, there are things you want to ask the doctor but you don't want to ask the doctor stuff in front of your parents and it creates stress because you are afraid of your parents' reaction.

— Andrea



Time out for Definitions

lol, cultr, bff, bf4l, bcnul8r. You know your terms, now know your health care language too.

Chronic is a word that means lasts a long time.

Health condition is another way of saying disease or disability.

Some people refer to adolescents who have a chronic health condition as "youth with special health care needs." However, most teens do not like the term "special" when it is used to describe them.

Families

There are all kinds of families. Some teens live with one or both of their birth parents. Some live with adoptive, foster or stepparent(s). Some live with one or more grandparents, other relatives or family friends. There are all kinds of parents and families. If the terms used in the next sections of this guide don't fit your family living situation, just substitute the ones that do.

Pediatrician — A doctor who is trained to take care of infants, children and teens.

Family Physician — A doctor who is trained to provide primary care to both children and adults.

Internist — A doctor who is trained to take care of adults.

Primary Care Provider (PCP) — A doctor who takes care of patients for many years and knows about all of their health care needs.

A PCP can take care of many of the health care problems that people have and help patients find a "specialist" if they need special tests or special kinds of medical services. Everyone should have a primary care provider who can help them get the health care that they need.

Specialist — A doctor who treats one kind of health problem or treats problems with one part of the body.

For example, an oncologist is a specialist that cares for patients with cancer. A cardiologist takes care of problems with the heart. Specialists usually do not deal with health problems that are not in their area of specialty.

Health Care Transition — The process of getting ready to leave your pediatric doctors and get your health care from doctors who are trained to care for adults.

More stuff about Transition

Reproduced in part, by permission of the Health Care Transition Initiative of the Institute for Child Health Policy (ICHP) at the University of Florida. Authors: John G. Reiss, Ph.D. – Author (ICHP/UF), Randal Miller – Project Coordinator (ICHP/UF), Florida Department of Health, Children's Medical Services, Susan J. Redmon, R.N., M.P.H. – Programmatic Contract Manager.

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By reading this guide and completing the activities, you have started to be more in charge of your life and your health and are better prepared to do more of the things you want to do now and in the future.

CSHP Health Care Transition Worksheets. These worksheets will help you and your family think about future goals and identify the things that you are doing now to be more in charge of your health. These worksheets will also help you to figure out what else you and your family need to do now and over the next few years so that, when you are a young adult, you are prepared for the transition from pediatric to adult-oriented health care; and that you are ready for work and living more independently.

On the Web

Children's Special Health Program Web Site www.cshp.dhw.idaho.gov

This web site has information about Children's Special Health Program.

Health Care Transition Training Web Site hetransitions.ichp.ufl.edu

This web site was developed by the University of Florida for teens, parents and professionals. It has lots of information about transition and some videos about teens who have taken charge of their health.

Jim's Story

video.ichp.ufl.edu/JimStory2.htm

This 10-minute on-line video is about a young man with Cystic Fibrosis.

College and Beyond

video.ichp.ufl.edu/collegeandbeyond.htm

This 20-minute on-line video is about Jeff, a young man who has a severe physical disability. As he grew up, Jeff learned how to be in charge of his health and make medical decisions with his doctors. This helped him be able to be independent and successful at college. Now he is about to graduate and get a job!

Health and Ready To Work Web Site

www.hrtw.org

This web site has lots of information about being healthy and getting ready for the future!







Taking control of YOUR FUTURE

IT'S TIME TO BE MORE IN CHARGE OF YOUR HEALTH CARE

Whereever you're going from here, you have more responsibilities; things like keeping track of assignments and homework or work hours. This shift in responsibility (from your teachers and your parents to you) is to help you prepare for college or vocational training, work and your future independence.

Since you have learned how to be more responsible and do more things for yourself in school, it's a good time to start taking more responsibility for your own health.

You know that you need to be as healthy as you can, in order to learn in school, hang out with friends, and do all the other things that you want to do.

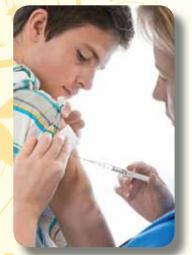
On the other side of this page you checked off some of the things that your family does now to help you be healthy.

Take a look at that list again, and think about the things that you can do right now or want to learn how to do this year, so that you can be more in charge. You can write down some of the things you would like to do for yourself, or learn how to do.









As you have probably heard from your family, making sure that a teen who has a chronic health condition (*like diabetes, asthma, cystic fibrosis, and epilepsy*) gets needed care can take a lot of planning.

Below are some things that families do for a teen who has a chronic health condition.

Put a check by the things that your family does to help you be healthy.

My parents or another member of my family:



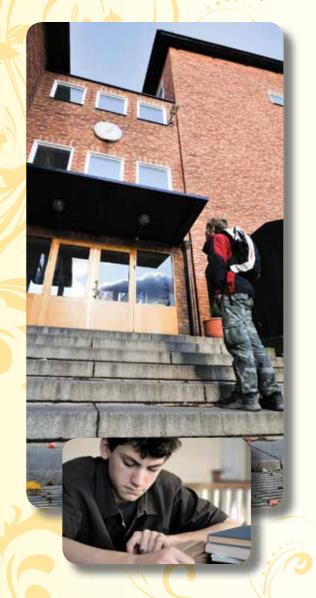
- ☐ Tell me when to take my medications
- ☐ Order my medications when I need more
- $lue{}$ Schedule appointments with my doctors
- ☐ Take me to my medical appointments
- $lue{}$ Come into the examination room with me
- ☐ Tell the doctors about how I am feeling
- ☐ Answer the questions that the doctors ask
- ☐ Ask the doctors questions about my condition
- ☐ Take notes about what the doctors say
- ☐ Remember what the doctors say to do
- ☐ Explain to me about my health condition
- ☐ Read books to learn more about my condition
- ☐ Look things up on the Internet about my condition
- ☐ Keep a notebook that has information about my health care (for example, my diagnosis, medications I take, names and phone numbers of my doctors)



/	



Responsibility & Freedom



Most teens say that they have more responsibilities in high school.

Most high schools are big and busy. You have a different teacher for every class – and you have to find your way from classroom to classroom.

You have more responsibility for keeping track of your assignments and homework.

You probably use a notebook to write down and keep track of your assignments and other things you need to remember.

And many teachers and parents say that teens in high school get to make more decisions for themselves and have a lot more freedom. maybe too much freedom.

And most teens have heard:

"With privileges come responsibilities and consequences."

They say these responsibilities and consequences get you ready to be an adult and have a job and be on your own.





Responsibility, Privileges © Consequences

Write down some of the things you are responsible for at home and at school and the privileges you earn if you meet your responsibilities and the consequences that you face if you do not... and if you think the responsibilities and consequences are fair or are not fair.

	H Home	At School
-		
Responsibilities		
(fair/not fair)		
-		
Privileges		
Privileges (Stuff I get to do)	0	
	en o	
Consequences (fair/not fair)		



Imagine your Life as an Adult



Another way of looking at yourself is to think about some things in your future — like how long you want to go to school, what kind of job you want, and where you want to live. *Below are some questions to ask yourself.*

Sch	ool	and	Worl	3
-----	-----	-----	------	---

I plan to finish high school

☐ Yes ☐ Maybe ☐ No

I plan to get vocational training

□ Yes □ Maybe □ No

I plan to go to college

☐ Yes ☐ Maybe ☐ No

I plan to have a job when I am an adult

☐ Yes ☐ Maybe ☐ No

What kind of jobs would you like to have?

Where I Will Live

In my own house or apartment (with roommates or by myself)

☐ Yes ☐ Maybe ☐ No

With my parents

☐ Yes ☐ Maybe ☐ No

With other members of my family

(brother, sister, aunt)

 \square Yes \square Maybe \square No Another place (specify):

Living Independently

Be financially independent

(support myself)

☐ Yes ☐ Maybe ☐ No

Drive a car

☐ Yes ☐ Maybe ☐ No

Get married or have a steady partner

□ Yes □ Maybe □ No

Raise a family

☐ Yes ☐ Maybe ☐ No

Have lots of friends

□ Yes □ Maybe □ No







What do Others Think



Another way of looking at yourself is to think about what other people think you are like – your classmates and friends, the people in your family, your teachers and others. Below are some words people might use to describe you. Check the ones you think apply to you or write in your own.

	Ho	W De	Ye	li li		ik C	the	is S		You?
My best friend	☐ Cool ☐	Thoughtful Trustworthy Frustrated	☐ Angry ☐ Caring ☐ Weird	☐ Loving ☐ Smart ☐ Nosy	☐ Timid ☐ Sad ☐ Kind	□ Peaceful□ Powerful□ Sneaky	□ Confused □ Organized □ Stubborn □ Mixed Up □ Persistent	☐ Neat ☐ Smart ☐ Sassy	☐ Silly ☐ Fun ☐ Open	☐ Forgiving ☐ Dependable ☐ Emotional ☐ Flexible
My favorite teacher	☐ Cool ☐	Thoughtful Trustworthy Frustrated		☐ Loving ☐ Smart ☐ Nosy	☐ Timid ☐ Sad ☐ Kind	☐ Peaceful☐ Powerful☐ Sneaky	□ Confused □ Organized □ Stubborn □ Mixed Up □ Persistent	☐ Neat ☐ Smart ☐ Sassy	☐ Silly ☐ Fun ☐ Open	☐ Forgiving ☐ Dependable ☐ Emotional ☐ Flexible
My parents	☐ Cool ☐	Thoughtful Trustworthy Frustrated	☐ Angry	☐ Loving ☐ Smart ☐ Nosy	☐ Timid ☐ Sad ☐ Kind	☐ Peaceful☐ Powerful☐ Sneaky	☐ Confused ☐ Organized ☐ Stubborn ☐ Mixed Up ☐ Persistent	☐ Neat ☐ Smart ☐ Sassy	☐ Silly ☐ Fun	
Teacher in my worst class	\square Cool \square	Thoughtful Trustworthy Frustrated		☐ Loving ☐ Smart ☐ Nosy	☐ Timid ☐ Sad ☐ Kind	☐ Peaceful☐ Powerful☐ Sneaky	□ Confused □ Organized □ Stubborn □ Mixed Up □ Persistent	☐ Neat ☐ Smart ☐ Sassy	☐ Silly ☐ Fun	☐ Forgiving ☐ Dependable ☐ Emotional ☐ Flexible
My brother(s) or sister(s)	☐ Cool ☐	☐ Thoughtful ☐ Trustworthy ☐ Frustrated		☐ Loving ☐ Smart ☐ Nosy	☐ Timid ☐ Sad ☐ Kind	☐ Peaceful☐ Powerful☐ Sneaky	□ Confused □ Organized □ Stubborn □ Mixed Up □ Persistent	☐ Neat ☐ Smart ☐ Sassy	☐ Silly ☐ Fun	☐ Forgiving ☐ Dependable ☐ Emotional ☐ Flexible
My neighbors	☐ Cool ☐	Thoughtful Trustworthy Frustrated	□ Angry □ Caring □ Weird	☐ Loving ☐ Smart ☐ Nosy	☐ Timid ☐ Sad ☐ Kind	□ Peaceful□ Powerful□ Sneaky	□ Confused □ Organized □ Stubborn □ Mixed Up □ Persistent	☐ Neat ☐ Smart ☐ Sassy	☐ Silly ☐ Fun ☐ Open	☐ Dependable☐ Emotional
People who don't know me	☐ Cool ☐	☐ Trustworthy ☐ F <mark>rustrated</mark>	☐ Angry☐ Caring	□ Loving □ Smart □ Nosy	☐ Timid ☐ Sad ☐ Kind	☐ Peaceful☐ Powerful☐ Sneaky	☐ Organized	☐ Neat ☐ Smart ☐ Sassy	☐ Silly ☐ Fun	☐ Dependable☐ Emotional
My doctors	□ Cool □	Thoughtful Trustworthy Frustrated	☐ Caring	□ Loving □ Smart □ Nosy	☐ Timid☐ Sad☐ Kind	☐ Peaceful☐ Powerful☐ Sneaky	□ Organized□ Stubborn	☐ Neat ☐ Smart ☐ Sassy	☐ Silly ☐ Fun	☐ Forgiving ☐ Dependable ☐ Emotional ☐ Flexible

Talking with The Doc



NOW is a good time to get ready to be more in charge of your next visit with a doctor.

Here are some things you should be able to do at a medical visit.

- Spend some time alone with the doctor (without your mother or father or other adult).
- Let your doctors know when you don't understand.
- Ask your doctors for answers to the questions you have about your health.
- Answer many of the questions that the doctor asks about how you are feeling and how you have been doing.

If you think about it, your doctors probably ask about the same stuff every time you see them.

First

Write down the questions that your doctors ask at every visit. It's okay to ask your family for help remembering what these questions are.

Second

Now pick one or two questions you would like to answer at your next doctor's visit. Let your parents know that you would like to be the one to answer these questions. Try writing down what your answer would be.

		= •		
Write	out the	questions	6	unswers

If the doctor asks:	
I could say:	
If the doctor asks:	
I <mark>could say:</mark>	



What to say when YOU DON'T UNDERSTAND



Sometimes it's hard to understand and remember what the doctor tells you. Sometimes they use words you don't really understand. Sometimes they talk too fast. Sometimes they give you way too much information. Sometimes they don't really answer the question you ask. Sometimes it's easier to remember if you can read something, rather than having them give you a lecture.

Since doctors really do want their patients to have the information they need to be healthy, you need to let them know when you really don't understand what they are talking about.

If you don't understand, you might say:

- Prease tell me more about that.
- What does that wean in simple English?
- Could You explain that to me again?
- COULD YOU WRITE THAT DOWN FOR ME?
- WHERE CAN I FIND MORE INFORMATION ABOUT THIS?
- Is there something you can give me to read?

Wh	What else could you say when you don't understand?							
_								



To see how you have changed, think about how things were when you were in middle school. Below, write down how you spend your time, what you do and what and who is important to you now — and how things were back then. In some ways you are different and in other ways you may be the same.

	Dom	Middle School
Outside of school my favorite things to do are		
At school I'm "into"		
Music I like		
My favorite TV shows		
My favorite book		
Best subject in school		
What I'm really good at	.0	
What I worry about most		
Who I'd like to meet		
My favorite movies		
Career I'd like to have		
Chore I hate most		
What keeps me going		

Now that you are Fifteen Youth transition plan worksheet

Health		Things I need to know or do	Will someone else have to do this for me	I will finish ? by (date)	Done
1. I understand my healthcare needs. Y	N		Y N		
2. I explain my special needs to others. Y	N		Y N		
3. I tell the doctor how I am doing and can answer his questions.	N		Y N		
4. I know the name of my doctor(s).	N		Y N		
5. I take my medicine with supervision.	N		Y N		
6. I know the name(s) of the medicine I take and possible side effects.	N		Y N		
7. I know when I am sick.	N		Y N		
8. I carry a copy of my insurance card.	N		Y N		
9. I carry a summary of my medical information with me.	N		Y N		
10. I am learning to schedule my own appointments.	N		Y N		

Independent Living				Things I need to know or do	Will someone else have to do this for me?		I will finish by (date)	Done
1.	I care for my own personal needs or know how to ask for them.	Y	N		Y	N		
2.	I know my phone number and address.	Y	N		Y	N		
3.	I know how to get help in an emergency, including calling 911.	Y	N		Y	N		
4.	I am responsible for doing my homework.	Y	N		Y	N		
5.	I think about what I want to do when I grow up.	Y	N		Y	N		
6.	I am <mark>lea</mark> rnin <mark>g to</mark> make choices.	Y	N		Y	N		
7.	I spend time with friends.	Y	N		Y	N		
8.	I do chores at home.	Y	N		Y	N		

